

A Perfect Match: A Content Analysis of Tweets Regarding Bone Marrow and Stem Cell
Registration and Donation

By

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Thesis

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Abstract of A Perfect Match: A Content Analysis of Tweets Regarding Bone Marrow and Stem Cell Registration and Donation

by Mikaila Singleton, MPH, Brown University, May 2021

Social media plays a vital role in the dissemination of health information. This research paper aims to provide new insight into how Twitter is used as a tool to spread both accurate and inaccurate messages about bone marrow/stem cell donation, offer evidence based strategies for how social media can be used to increase donation rates in young and minority populations, and present guidance for future research. A content analysis of manifest and latent themes was performed using the advanced search function of Twitter to find relevant Tweets. We examined 12 variables in a total of 87 Tweets. A quantitative analysis was also performed to examine associations between select post characteristics and engagement. The results of the analysis indicated that information presented in posts was generally accurate. However, 1 in 9 Tweets contained some aspect of misinformation. Four major themes were identified in Twitter posts; only the theme of urgency was found to be significantly associated with engagement. In conclusion, Twitter has the potential to inform and encourage a wide audience to sign up for the bone marrow and stem cell registry, as well as to complete the donation process if selected. Future research is needed to identify specific characteristics of Tweets that are tied to higher levels of engagement to allow individuals and organizations to target their message to the largest audience.

Table of Contents

Introduction.....	1
Methods.....	3
Results.....	4
Discussion.....	16
References.....	20

List of Tables and Figures

Figure 1: Source of Twitter Post.....	4
Figure 2: Media Attachments.....	5
Figure 3: Subject of Media Attachments.....	6
Figure 4: Subject of Post.....	6
Figure 5: Type of Disease.....	7
Figure 6: Donor/Potential Donor Gender.....	7
Figure 7: Donor/Potential Donor Age.....	8
Figure 8: Recipient/Potential Recipient Gender.....	8
Figure 9: Recipient/Potential Recipient Age.....	8

Introduction

A bone marrow or stem cell transplantation can be a life-saving treatment option for individuals with life-threatening diseases, such as leukemia and lymphoma, that prevent their body from producing healthy blood cells. Stem cells are immature cells formed in the bone marrow and develop into three types of cells: (1) red blood cells which carry oxygen, (2) white blood cells which fight infection and (3) platelets which help blood clotting. A transplant works by replacing defective blood cells with healthy ones. Finding a transplant match is based on the human leukocyte antigen (HLA) tissue type. HLA type is made up of 5 genes, and each one of these genes has 2 different alleles for a total of 10. HLA markers help the body differentiate normal cells from foreign cells, such as cancer cells. Not all matches are equally effective. A close match between HLA markers of the donor and patient improves the chances of a successful transplant compared to a less-close match. Less close matches increase the risk of developing certain post-donation complications, such as graft-vs-host disease.

In the United States, approximately 18,000 people per year are diagnosed with life-threatening illnesses, such as leukemia and lymphoma, where a bone marrow or stem cell transplant is their best or only treatment option. Of these individuals, only about 30% will have a relative who is a match and is able to donate, leaving the lives of many in the hands of a stranger on the registryⁱ. However, due to varying donation rates in different populations and the commonality of certain HLA types over others, not everyone has an equal chance of finding a matched donor. In particular, the likelihood of an individual finding a match largely depends on race and ethnicity. This is because HLA markers are inherited, most commonly making someone's best chance at a match with someone of their same ethnic background. Unfortunately, a wide range of socio-

cultural barriers to donating has created large racial/ethnic disparities in bone marrow matches. According to data from Be the Match, the largest stem cell and marrow donor registry, while white patients have a 77% chance of finding a match on the registry, this percentage drops to 46% for Hispanic/Latinos, 41% for Asian and Pacific Islander, and just 23% for Black patientsⁱⁱ. Additionally, the coronavirus pandemic has resulted in a reduction in both registrants and donors as well as a surge in need for bone marrow transplants. Thus, it is vital to increase awareness of the bone marrow registry and encourage more individuals-particularly of minority backgrounds-to join the registry as potential future donors.

Social media is a proven tool for spreading awareness and motivating action and has sparked many examples of medical altruism among its users. The story of a patient “John Smith” is one example. When Smith was diagnosed with Leukemia in September 2011, he faced slim odds of finding a matching bone marrow donor as South Asians are dramatically underrepresented on the registry. However, with over 17,000 Twitter followers and 13,000 Facebook friends, he had a large network of people to help spread awareness of his need for a transplant. Not only did Smith find a match, but his social media campaign also inspired about 10,000 new potential bone marrow donors to registerⁱⁱⁱ.

Twitter holds huge potential for the study of the spread of health information as it is the number one social media for news consumption. Additionally, Twitter users are primarily young adults who also are the most likely to produce successful donation results after registering^{iv}. Of note, anyone is able to post on Twitter, and there are only limited protective measures in place to ensure the validity of posted content. Expertise, ethics, and accuracy of Tweets containing health information may at times be lacking. Such posts are disseminated instantaneously and may

persist permanently on the internet. This research paper aims to identify new insight into how Twitter is used as a tool to spread both accurate and inaccurate messages about bone marrow/stem cell donation, offer evidence based strategies for how social media can be used to increase donation rates in young and minority populations, and present guidance for future research.

Methods

A content analysis of manifest and latent themes was performed using the advanced search function of Twitter to find relevant tweets posted between August 1st 2019-August 1st 2020 related to bone marrow and stem cell donation. These dates were chosen to reflect the most recent trends as well as to allow for an analysis of how the Covid-19 pandemic impacted donation related information. The search was conducted using the keywords ‘stem cell donor’, ‘stem cell donation’, ‘bone marrow donor’, ‘bone marrow donation’, ‘cord blood donor’, and ‘cord blood donation’. English language tweets were included if: (1) The Tweet contained one of more of the keywords previously mentioned related to human donations (2) The Tweet was a primary post(as opposed to a reply to another post) and (3) The Tweet was posted between August 1st 2019-August 1st 2020. Tweets were assessed in order of appearance on the “Top” tab of the search page-an indication of the popularity of the Tweet. For the content analysis, we examined 12 variables: 1) the date, 2) source of the post, 3) verified status of the poster, 4) presence of attached media, 5) subject of the post, 6) primary message, 7) emotions conveyed, 8) condition for which donation is needed, 9) additional hashtags, 10) level of engagement, 11) presence of statistics and 12) presence of misinformation. All Tweets were analyzed by the first author; a sample was analyzed by faculty advisors; discordant assessments were adjudicated to achieve consensus.

The quantitative analysis was performed using R. We first calculated descriptives of the main variables of interest. We then conducted independent samples t-tests to examine differences in likes and retweets between groups based on particular Tweet characteristics and themes.

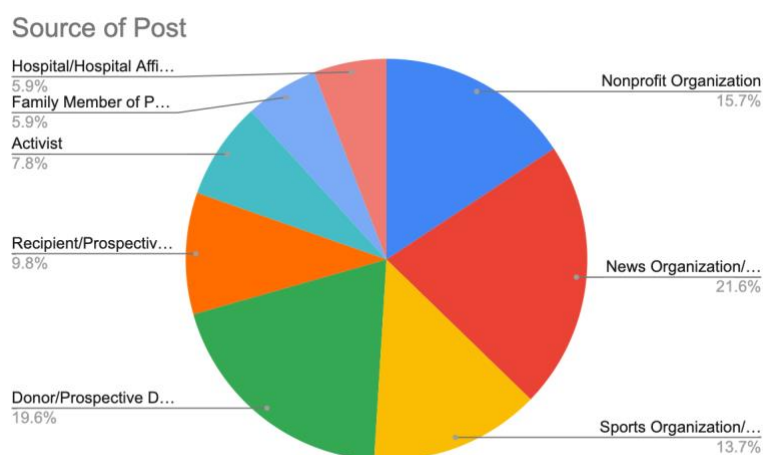
Results

A total of 87 Tweets posted between March 12th 2020 and August 30th 2020 were assessed.

Although the original search date was August 1st 2019-August 1st 2020, the earliest Tweet resulting from the Twitter “Top” search algorithm was March 12th 2020. Of these, 81 Tweets met the inclusion criteria and 6 Tweets were excluded from the analysis because their primary focus was not bone marrow or stem cell donation.

The distribution of Tweets that used the key term bone marrow (58.6%) vs stem cell(44.8%) was relatively equal with a slight preference toward the term bone marrow. Language seemed to be associated with geographical location-with use of the term stem cell being heavily biased toward users from the UK.

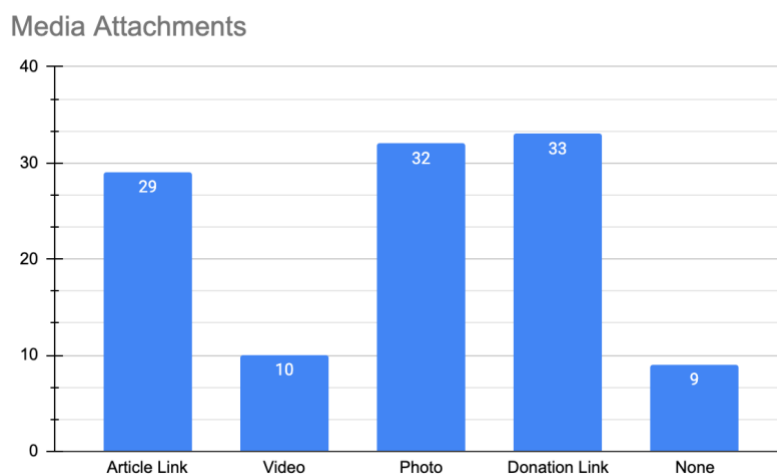
Source of post



Over half of the included Tweets (63.0%) came from sources that could easily be identified via the user's profile. Of these, the highest number of posts came from news organizations and individual representatives of the news (21.6%), closely followed by individuals who have donated or registered to donate bone marrow or stem cells (19.6%). Nonprofit organizations (15.7%) and sports organizations and players (13.7%) also produced a substantial percentage of identified tweets-followed by prospective or past bone marrow recipients (9.8%), bone marrow activists (7.8%), family members of patients (5.9%), and hospitals/affiliates (5.9%).

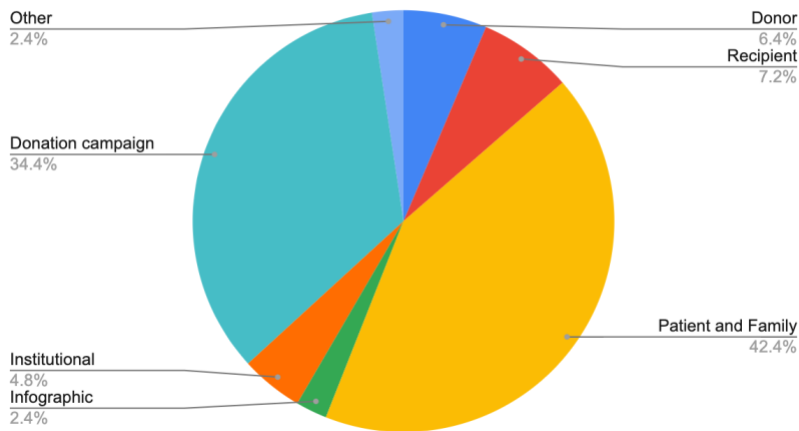
Additionally, 40.7% of included Tweets came from verified users and 59.3% from unverified users. A verified account is indicated by the signature blue verified badge, and lets people know that an account of public interest is authentic.

Attached Media



Almost 90% of included Tweets had some sort of attached media (88.8%). Because a single Tweet can contain multiple types of media, the proportion of attachments by media type does not add up to 100%. There was a fairly equal distribution between article link attachments, photos, and donation links. A relatively small number of tweets included attached videos, excluding article links that also had video coverage of the featured story.

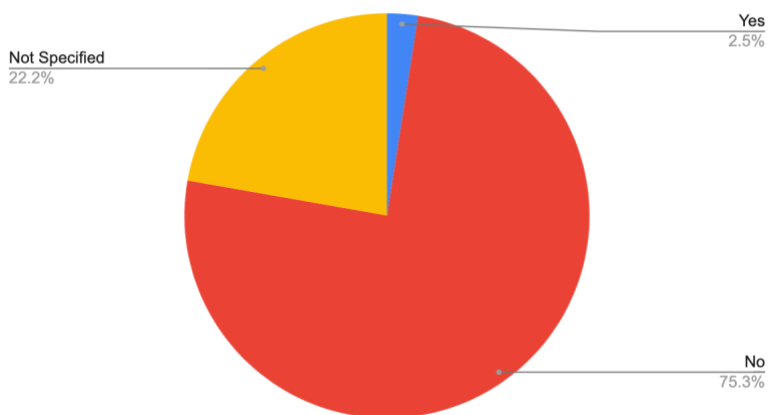
Subject of Media



Almost half of the media attachments (e.g., photos, videos, and links) were focused on patients and their family (42.4%), and over a third included individual donation campaigns (34.4%). Other media content areas that were used less frequently were recipients (7.2%), donors (6.4%), institutional campaigns(4.8%), and infographics(2.4%).

Subject of Post

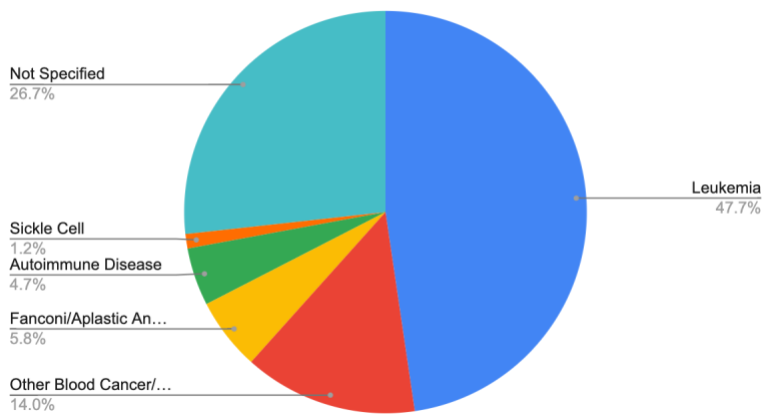
Related Donation



About 75% of posts described a donation from a non-relative. This number is representative of the national average in which about 70% of stem cell donations are from individuals not related

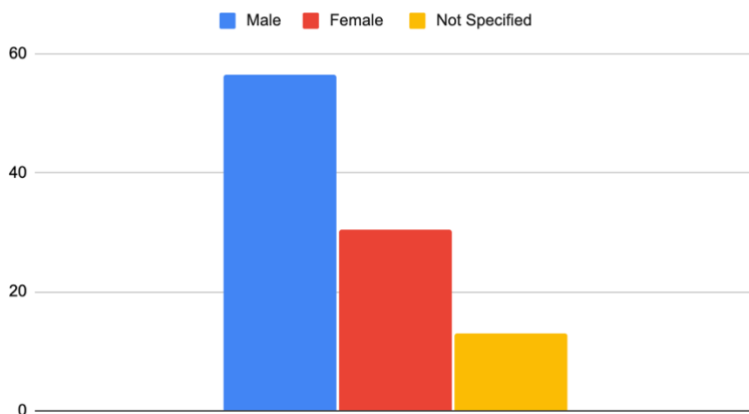
to the recipient^v. Only 2.5% of posts described a donation between family members, and the rest of Tweets did not specify whether the donation was from a relative or not.

Disease

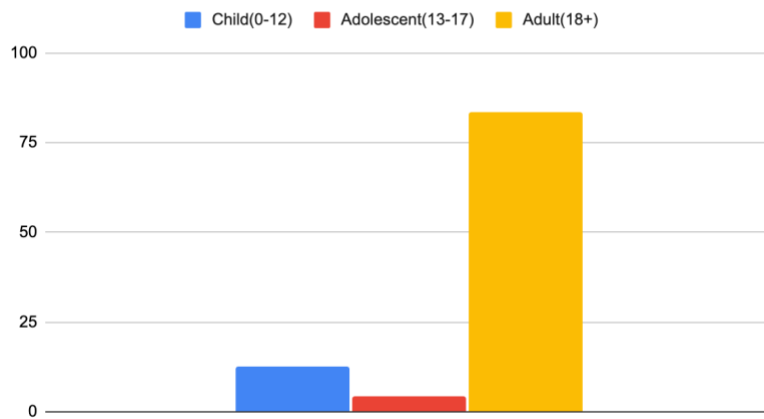


Leukemia was the most commonly referenced disease in relation to the need for a stem cell/bone marrow transplant. Almost half of the Tweets referenced patients with leukemia (47.7%). Followed by other blood cancers and diseases (14%), anemia (5.8%), autoimmune diseases (4.7%), and sickle cell (1.2%) respectively.

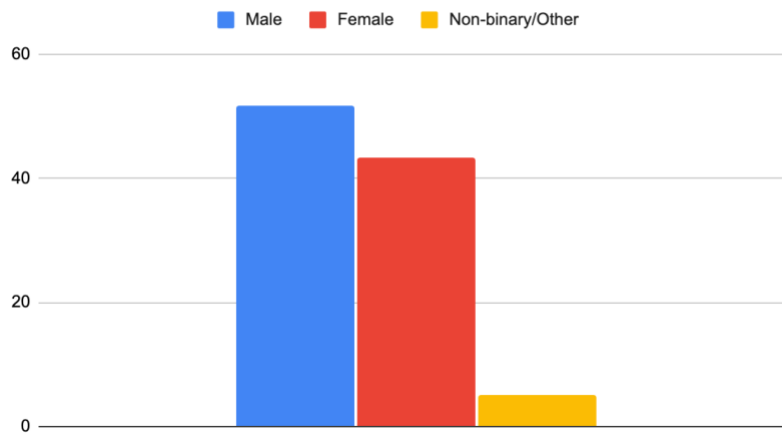
Donor/Potential Donor Gender



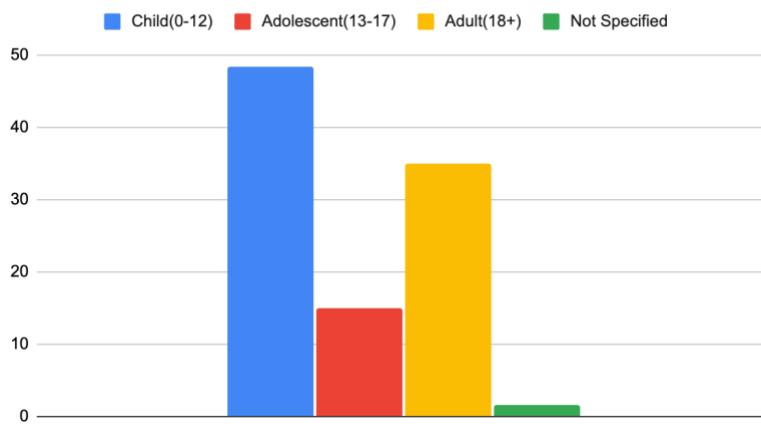
Donor/Potential Donor Age



Recipient/Potential Recipient Gender



Recipient/Potential Recipient Age



There were almost double as many Tweets regarding male donors/potential donors than female donors. Of the 23 Tweets that referenced gender of donors, 56.5% were about male donors or potential donors while only 30.4% were for female donors. As expected, the vast majority of posts were focused on adult donors since many registries require non-related donors to be 18 years or older. The gender breakdown of Tweets regarding recipients/potential recipients was much more evenly distributed. 60 Tweets referenced gender of recipients. Of those Tweets, 51.7% referred to male recipients, 43.3% to females, and 5.0% to individuals with other gender identities. There was also more variety in the age range of recipients, with the majority of Tweets being about children in need of a donor, followed by adults and adolescents.

Messages, Emotions, and Themes

Seeking donor registration--The most popular message identified was the encouragement of individuals to sign up for the bone marrow/stem cell registry and become potential donors. Eighty-four percent of Tweets were made with the intention of motivating people to register and donate. Common strategies of encouraging people to register included, posting a link to the website of a national or worldwide registry or posting links to person-specific web pages on the registration website. These pages incorporated photos, videos, and personal information about a specific individual currently in need of a donor. Emotional appeals were common. There were also cases in which Tweets provided readers with a code to text, and they would subsequently be sent information on how to sign up for the registry.

In order to include individuals who were unable to donate for health reasons, a few posts provided other ways to support individuals in need of a bone marrow or stem cell donor. The most common included financial donations to families to cover healthcare expenses, financial

donations to registries to cover the cost of processing registration kits, and sharing Tweets on social media to spread awareness to potential donors.

Education about the registry and donation process--Education was another prevalent message identified in the Tweets. Twenty-two percent of Tweets featured some educational component, most commonly centered on how to sign up for the registry and what the donation process is like. Posts also addressed how a match is determined and how bone marrow/stem cells can be used as a treatment option for people with chronic diseases. In terms of who is most needed to sign up for the registry, many posts emphasized the need for more young men and people of color to donate. Additionally, a few posts specifically were aimed at dispelling common misconceptions. Some examples of these misconceptions are: having to pay to become a donor, substantial pain associated with the donation process, and a bone marrow biopsy as a requirement for donor registration.

Donation stories-- 22.2% of posts consisted of users sharing their personal stories of bone marrow and stem cell donation. In some cases, these stories were from the perspective of the donor, such as a user that shared his entire registration process and ultimately discovered that he was a match for a three year old boy. Other Tweets told a similar story from the perspective of the recipient who received a life-saving transplant. All of these posts were uplifting and highlighted emotions of hope and thankfulness of both the recipient and the donor.

In order to convey these three primary messages, Tweets often attempted to appeal to people either by eliciting feelings of inspiration or otherwise emotionally moving readers. In fact, 70.4% of Tweets utilized this strategy. One way in which this is accomplished is through the language used about bone marrow and stem cell donors. 82.7% of Tweets used heroic language to describe donors-either by referring to them as heroes, life-savers, or emphasizing the importance of their

gift. Posts also often made mention of babies/children, included pictures of individuals and their families, or gave readers specific actions that they could take to aid a situation. One example that stands out is the story of Susie X. Susie battled leukemia, and got over 85,000 people to sign up for Be the Match using social media. However, after giving birth to twins, she died. While this is a heartbreaking story, Tweets encouraged people to donate to a GoFundMe for her children. This GoFundMe raised over \$35,000-exceeding its goal-by empowering readers to take action. Additionally, four main themes were found in Tweets that were analyzed. The themes of simplicity/ease of donating, Covid-19, and racial/ethnic disparities were established *a priori* based on the importance of these topics in the literature and significant presence in an initial evaluation of related Tweets. The theme of urgency was added to the coding guide after it became apparent that this theme was present in >10% of included Tweets.

Simplicity/ease of donating--35.8% of Tweets emphasized the speed and ease of signing up for the registry and becoming a bone marrow/stem cell donor-especially in comparison to past methods. There still exists the false belief that painful bone marrow biopsies are still a necessary part of the donation process. However, in most scenarios, this is no longer the case. Posts regarding signing up for the registry often mention how it is as simple as a quick cheek swab. For example, one user says “one simple registration can save someone’s life.^{vi}” The post includes an infographic that describes stem cell registration and donation as easy and painless. There is also a growing effort to mitigate the stigma and fear associated with the donation process by comparing it to giving blood, which is a far cry from the painful extraction process that many still imagine.

Covid-19--The impact of the pandemic was addressed in 28.4% of Tweets. Many organizations noted the impact that coronavirus has had on donor registration, with the number of people

signing up to be potential donors drastically falling. As traditional, in-person donor recruitment events cannot be held due to coronavirus, it is increasingly difficult for individuals to find a match. Additionally, organizations such as the DKMS- an international nonprofit bone marrow donor center- reported increases in the number of patients requiring their support, as transplants that were deferred or postponed in the early days of the pandemic received the go ahead.

However, Tweets show evidence of some attempt to counter this barrier with the use of virtual registration and fundraising events. Donor centers also made attempts to reassure potential donors that their facilities were safe and practicing stringent sanitation procedures. Another factor to consider is the impact the pandemic has had on the emotional wellbeing of patients and their families. Many posts describe the difficulty of battling cancer physically away from loved ones, the struggle of isolation, and hospital limitations on the number of visitors. The story of Liya, a little girl in desperate need of a stem cell donor, is mentioned in a number of Tweets. Because Liya was diagnosed with Leukemia at the beginning of the pandemic, only one parent was allowed to be with her throughout her treatment. Her mother describes the emotional toll of coping with both the pandemic and her daughter's diagnosis, as well as how Coronavirus has impacted Liya's chances of finding a match. Her mother notes "I know that it's a tough time that we're going through with all this lockdown, but all these kids need blood transfusions and they need just basic help really."^{vii}

Racial/ethnic disparities-- There is a great need for more young people of minority racial and ethnic backgrounds to join the bone marrow/stem cell registry. Due to the connection between HLA type and genetics, individuals are most likely to find a match of their same ethnic background. Currently there are significant racial and ethnic disparities in the likelihood of finding a matching donor. These disparities are highlighted by a number of Tweets. 22.2% of

analyzed posts made note of existing disparities, most often for individuals of African, South Asian, or Ashkenazi Jewish descent. In an interview about the need for greater diversity of bone marrow donors, the CEO of an Australian registry sums it up well when he says “We have to reflect the Australian population, so more diversity gives us options to help more people across the country.”^{viii}

Urgent need--While bone marrow and stem cell transplants are often time sensitive issues, 22% of analyzed Tweets emphasize this urgency either through language indicating dire circumstances or by specifically stating a timeline in which the transplant must occur. Specific timelines like this are highly unlikely to be provided by a physician, and thus are one sign of potential misinformation. One Tweet says “Nottinghamshire girl, 14, 'has weeks' to find a bone marrow donor” and includes information about the teenager who is in desperate need of a donor.^{ix} Posts like this might actually be providing readers with a misrepresentation of the situation, as it is likely too late for any new donor registrations to have any effect for the individual described in the Tweet. Users are recruited to join the registry using an inflated notion of their likelihood to be able to help a specific person. In actuality, when someone signs up for the registry, the probability of them being an unrelated match for that specific individual is no greater than the probability that they are a match for any of the thousands searching daily. Other timelines were much broader, such as in the case of a little boy who noted that if he was unable to find a match by the end of the school year, he would make the choice to stop treatment and enjoy the time he had left with his loved ones. In both cases, this urgency is an attempt to encourage readers to take necessary action, such as signing up for the registry or sharing the post, now rather than later.

Information and Misinformation

While the majority of Tweets did not utilize statistics to convey their messages, the ones that did (30.4%) were all verified using evidence-based outside sources to be accurate representations of information. The most common statistics were concerning the lack of available donors for Black, Asian, and Latinx people. Other popular statistics included the likelihood of an individual finding a match within their family and the proportion of the population on the national registry. Despite the general accuracy of statistics, there were a number of Tweets containing aspects of misinformation-defined as false information that may accidentally or purposefully mislead. Eleven percent of coded Tweets contained misinformation. Misinformation exists in many different forms. The most common type of misinformation presented in the analyzed Tweets were misleading information and the presence of spin. These Tweets tended to do one of two things. The first was to establish bone marrow and stem cell donation as a process that is always pain free for the donor, when this is not necessarily the truth. One example of misinformation is when one user who was seeking a bone marrow donor for her brother wrote “Registering takes 5 minutes and entails a free mail-in cheek swab you do from home. Donating itself is also easy and painless (despite what you may think) -- similar to donating blood.”^x However, while about 79% of donors now donate via a nonsurgical peripheral blood cell donation, that is similar to donating blood, others still have to donate through the traditional surgery-which is not without pain. Additionally, even the nonsurgical procedure involves medication which is often associated with some pain for the donor. The second use of misleading information occurred in Tweets that presented a very narrow time-frame in which an individual needed to find a donor, and encouraged readers to take immediate action to help this individual. These Tweets are misleading because they lead readers to believe that by joining the registry, they could potentially be the life-saving match for the individual mentioned in the Tweet.

However, it typically takes two months to process a new registration kit and between four-to-six weeks to complete the donation process^{xi}. Thus, any individual reading the Tweet will not be able to complete these steps in the necessary time-frame. Additionally, an individual registering today is just as likely to be a match for anyone on the registry, not just the individual in urgent need. Rather, by signing up, the individual will simply have the potential to save the lives of others in a similar circumstance.

Engagement

The overall distribution of likes ranged from 0-1800 with a median of 45 and a mean of 130 ($SD=291$). The distribution of retweets ranged from 0-1900 with a median of 16 and a mean of 87 ($SD=260$).

Tweets from verified Twitter accounts demonstrated higher levels of engagement than Tweets from non-verified accounts. The average number of likes on Tweets from verified users was 178 compared to 96 for unverified users. The average number of Retweets on Tweets from verified users was 117 compared to 66 for unverified users. However, P-values of .2154 and .3826 respectively indicating no statistically significant difference in Tweet engagement between verified and unverified users. Similarly, while inclusion of relevant statistics regarding the registry/donation resulted in higher Tweet engagement on average, this difference was also not found to be statistically significant in our analysis. Tweets that included statistics had an average number of 187 likes and 109 retweets compared to Tweets that did not include statistics which had an average number of 106 likes and 79 retweets. Inclusion of media content such as photographs or video was also not found to be statistically associated with increased engagement.

Additionally, the presence of all aforementioned themes were independently analyzed for an association with engagement. Tweets that used the theme of simplicity and ease of donation did have a higher number of likes and retweets on average than those that did not utilize this theme, however this difference was not statistically significant. On average, Tweets with the theme of simplicity/ease had 158 likes and 108 retweets compared to tweets without that had an average of 116 likes and 75 retweets. Tweets that mentioned the pandemic and the impact it has had on bone marrow and stem cell donation also had higher engagement on average. Tweets including this theme had an average of 186 likes and 136 retweets compared to tweets that did not mention the pandemic which had an average of 107 likes and 67 retweets. However, the independent samples t-test did not reveal and statistically significant differences in engagement between these two groups.

Tweets that mentioned racial and ethnic disparities in donor availability and donation rates appeared to be associated with higher Tweet engagement, particularly likes. Tweets that mentioned disparities had an average number of 220 likes and 115 retweets compared to an average of 104 likes and 78 retweets in those that did not, but again this difference was not statistically significant. Posts that used themes of urgency or time sensitivity seemed to be associated with less Tweet Engagement. Tweets using this theme had an average number of 52 likes and 62 retweets, compared to 154 likes and 94 retweets in Tweets without this theme. Notably, this difference was statistically significant for the number of retweets, with a p-value of .02.

Discussion

This content analysis illustrated the major characteristics and themes of Tweets regarding bone marrow and stem cell registration and donation. News and nonprofit organizations as well as

individuals who have already registered to donate stem cells or bone marrow were major contributors of Tweets on the subject. Seemingly absent, however, were physicians and other healthcare professionals. This finding is in line with a similar 2017 analysis examining Twitter trends in information regarding live organ donation. The authors discovered that healthcare professionals and hospitals were significantly less likely than donors and organizations to include transplant-related educational information in their profiles^{xii}. The presence of experienced healthcare professionals on social media could assist not only in countering aspects of misinformation, but could also serve as a source of engaging and accurate information for large audiences if employing effective Tweeting strategies.

The majority of Tweets included additional media content, such as photos, videos, or donation links, and primarily focused on encouraging readers to donate. Information presented in posts was generally accurate, but 11.11% of Tweets contained some aspect of misinformation. Four major themes were identified in Twitter posts, however, only the theme of urgency was found to be significantly associated with engagement. The theme of urgency being inversely related to engagement via retweets was counterintuitive because urgency has been shown in numerous psychological studies to encourage people to take action^{xiii}. However, the negative relationship could be tied to the fact that a narrow timeline and insinuation of imminent death was too negative for users to want to retweet or like and countered the individual desire to save a life. Notably, not all Tweets that included the theme of urgency were examples of misinformation. Tweets with specific individual timelines for finding a bone marrow or stem cell match that allowed for the completion of necessary steps a potential donor must take, or that simply used language indicating urgency/time sensitivity were not coded as misinformation.

While not statistically significant, Tweets that described the ease of the donation process and/or mentioned the pandemic were found to have more likes and retweets on average. This is not surprising based on evidence presented in the literature about barriers to donation and current research trends. Many studies have documented fear of pain as a barrier to donation among unrelated potential donors. One study examining factors associated with attrition from a national bone marrow registry found that fear of pain, damage to their own health, anesthesia, needles, and having to take time off work were all highly significant factors in deterring individuals from proceeding with the donation process^{xiv}. Thus, it makes sense that Tweets that emphasized the simplicity and relatively painless nature of the process would be appealing to users and have higher average levels of engagement. The increase in average engagement that we see in Tweets referencing coronavirus can likely be attributed to high levels of individual and research interest in Covid-19 related topics. Similarly, the pandemic has also brought increased attention to issues of racial and ethnic disparities in health and health care, which could explain the higher average engagement measures for these Tweets.

Based on the results of this research, we can offer a few recommendations for those seeking to use Twitter to spread awareness about the bone marrow/stem cell registry and/or to recruit potential donors. If the primary purpose of your Tweet is to immediately attract potential donors to the registry, it is likely beneficial to include a donation link in your post that individuals can easily access. Furthermore, explanations of the importance of other forms of support, such as financial contributions to registries are currently sparse, so it may be worthwhile to include this information as well. Additionally, the language used in the post should be very intentional.

While not found to be statistically significant, this analysis reveals some evidence to show a potential positive association between using statistics, mentioning racial/ethnic disparities in

donation rates, and describing donation or registering to donate as being a simple process.

Posters should be careful in ensuring that their Tweet does not contain any information that is too ambiguous, inaccurate, or misleading to readers.

This is the first Twitter based content analysis to study themes related to bone marrow and stem cell donation, and provides valuable insight into how social media is used as a tool to both spread health information and recruit new donors. The results of this study may also be relevant to other topic areas involving unrelated donors-such as blood donation and organ transplants. However, the study was limited by its small sample size. Although we coded all Tweets that appeared on the Twitter top search page, the algorithm used by Twitter to determine which content and engagement factors influence search queries is unknown, and perhaps means that the Tweets analyzed in this study are not entirely representative of Tweets as a whole. Additionally, some Tweets that were coded in our study may now be deleted since the time of our analysis. The analysis is limited by the use of only one independent coder of all Tweets, increasing the possibility of bias in the results. There is also a limitation in the scope of the analysis because only a select number of variables were tested for association with engagement.

Future research should expand on this work by identifying a wider range and more robust sample size of Tweets that may be tied to engagement. Developing a strong understanding of which components of a Tweet make users more likely to engage will be critical for individuals and organizations seeking to attract more potential donors-particularly young people and people of color to join the bone marrow and stem cell registries.

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